

## ***Emotionally Paralyzed: Struggles and Successes with Underdeveloped Coping Skills in Emerging Adults (TH312A)***

Keri Brenner, MD, MGH and Dana Faber Cancer Institute, Boston, MA

### **Objectives**

- Identify Erik Erikson's stages of development, and reflect upon how these stages are at work for coping responses and distress in emerging adults.
- Provide an assessment of the clinical barriers to a particular case of a young adult with metastatic disease, and also provide an assessment of the family dynamics at work.
- Show an ability to use psychologically informed techniques with various challenging emerging adult case scenarios

**Background:** Emerging adults are a newly identified and studied population with particular psychosocial and cognitive needs that present several challenges for the palliative care team (PCT).

**Case Description:** A 25 year-old male, computer software programmer, developed mediastinal Ewing-like sarcoma with metastases to liver and brain. After 16 months of treatment including chemo- and radiotherapy and resection of brain metastases he developed CNS and systemic disease progression.

The patient coped by intellectualizing, emphasizing cognition over emotion. Throughout his treatment he recorded in computer applications all symptoms and medications administered. He asserted control over which medications were in his body at what time, insisting on short-acting medications for pain and anxiety, refusing long-acting benzodiazepines or SSRIs. The patient insisted he was the only one entitled to express emotion, since he was the only one going through the dying process. He was infuriated whenever his girlfriend or parents became sad or upset. During one discussion about changing code status, he yelled at his tearful mother, “You just don’t want to be the one to pull the plug. Why is this all about you and your own guilt, when I am the one dying?” PCT was consulted early in treatment to help promote his comfort despite this dysfunctional coping.

The patient allowed comfort measures only three days before his death. With the help of the PCT, his family and girlfriend became much more expressive, shared uplifting memories, promoted laughter and open conversation about coping. They provided physical touch and comfort that he previously never allowed.

**Conclusion:** We will explore how to assess the unique distress and coping skills in emerging adults to overcome the specific barriers of this population. We will demonstrate how particular psychotherapeutic techniques and interventions can be useful to the PCT as they care for emerging adults with terminal illness.

## ***Improving Palliative Care for Rural America with Telemedicine: A case discussion and results from a qualitative feasibility study (TH312B)***

Anthony Cheng, MD, Oregon Health and Science University, Portland, OR  
Elizabeth Powers, MD, Oregon Health and Science University, Portland, OR  
Eric Walsh, MD, Oregon Health and Science University, Portland, OR  
Patricia Carney, PhD, Oregon Health and Science University, Portland, OR

### **Objectives**

- Describe how health disparities in rural America impact hospice and palliative care.
- Identify barriers and facilitators to the implementation of a telemedicine-based palliative care consultation service.

**Background:** Significant health disparities exist for patients in rural communities. Among them is reduced access to palliative care. We describe how an interdisciplinary team based in a rural hospital addressed this gap.

The Wallowa County Palliative Care Working Group consists of two physicians, two nurses and a community mental health worker. The group built upon regional partnerships to bring a home hospice agency into the community and collaborated with an academic health center to develop a palliative care consultation service using a telemedicine platform.

Because there are questions about the feasibility and acceptability of using telemedicine to deliver palliative care, this service was implemented according to a Consolidated Framework for Implementation Research. Semi-structured key informant interviews were used to identify barriers and facilitators to implementation. A logic model was developed and has guided a rapid cycle improvement strategy.

**Case Description:** A 67 year-old female living in a frontier community presented to her primary care doctor complaining of abdominal pain and constipation. Treatment of constipation did not relieve her pain. A CT scan of her abdomen and pelvis showed peritoneal carcinomatosis, an esophageal mass and ascites. She was diagnosed with stage 3B ovarian cancer and had initial chemotherapy and the cancer became resistant to platinum. She had a de-bulking procedure and second line chemotherapy with gemcitabine. She developed anorexia, fatigue and dyspnea as a result of the chemotherapy and decided to stop disease-modifying treatment. She enrolled in the newly available hospice and met with a palliative care specialist using a telemedicine linkage, all without leaving town. She has been taking Tibetan herbs and reports that her quality of life is very good.

**Conclusion:** Rural communities suffer from health care disparities and may lack access to home hospice and palliative care services. These disparities can be ameliorated with community and academic partnerships.

## ***Palliative Therapy Does Not Mean Intervention Free Therapy (TH312C)***

Jessica Casas, MD, The Children's Hospital of Philadelphia, Philadelphia, PA

Vanessa Battista, CPNP,MS,RN, Children's Hospital of Philadelphia, Philadelphia, PA

### **Objectives**

- Illustrate a case in which invasive surgical interventions may maximize quality of life in a terminally ill patient.
- Identify interventions for aggressive pain management using a collaborative team approach.

**Background:** Metastatic solid tumors can cause acute life threatening complications with associated shortened life expectancy and increase in morbidity. Palliative therapies may include invasive surgical interventions to maximize quantity and quality of life.

**Case Description:** A 22 year old male with relapsed Ewing Sarcoma presented with large bilateral pneumothoraces. He had diffuse pulmonary nodules, without other life-threatening lesions. Performance status was 100. The patient's goals were to maximize time with family at home. Given the certainty that the metastatic lesions would cause recurrent pneumothoraces, our team recommended bilateral pleurodeses in order to maximize quality of time at home without being restricted by bilateral chest tubes (CTs) to water seal. General surgery performed the right sided pleurodesis at the bedside with lorazepam and a hydromorphone PCA. The pain associated with this procedure was excruciating. Together with pediatric surgery, anesthesia, oncology, and the pediatric intensive care unit (PICU), left sided pleurodesis was completed under general anesthesia in the operating room for the first hour of the most intense pain, followed by admission to the PICU for the subsequent six hours of pain management with a ketamine infusion. Results were excellent and the patient was discharged to home on a fentanyl patch without CTs.

**Conclusion:** Palliative care requires "thinking outside the box" and may include seemingly invasive interventions with aggressive pain management in order to maximize time and quality of life in terminally ill patients. Collaborative team efforts are an essential component to effectively treat pain in cases when novel therapies are used.

## ***When the Operating Room is the Best Place to Die: the Role of Palliative Care in Donation after Cardiac Death (TH332A)***

Katharine Brock, MD MS, Dana Farber Cancer Institute, Boston, MA

### **Objectives**

- Define donation after cardiac death (DCD).
- Identify three strategies that the palliative care team can employ to assist families before, during, and after donation after cardiac death (DCD).
- Summarize three ways the palliative care team can collaborate with the medical teams and operating room environment for donation after cardiac death (DCD).

**Background:** An increasing number of pediatric centers are adopting policies for donation after cardiac death (DCD), but little is known about the role of pediatric palliative care (PC) during this process.

**Case Description:** CM is a 23-year old male with autism, intellectual disability, and epilepsy who was hospitalized after orthopedic repair of a hip fracture. Post-operatively, he developed renal and respiratory failure with multiple pneumothoraces supported by dialysis, intubation, mechanical ventilation, and five chest tubes.

After four weeks, with recovery unlikely, pediatric PC worked with the family to articulate their goals for comfort-focused care. His family chose to discontinue life-sustaining technologies. As a legacy, his family expressed interest in DCD.

The PC team prepared CM's family for DCD by discussing memory making, family presence in the operating room (OR), the extubation process, and strategies to ensure CM's comfort. Preparation also occurred around the challenges of the OR environment (e.g. staff presence and sense of sterility) and the potential for a feeling of a secondary loss if death did not occur within 60 minutes. Chaplaincy, nursing, the local organ bank and social work assisted in preparing keepsakes, siblings and memorial planning.

The PC team collaborated with critical care and surgery staff regarding comfort medications to administer in the OR, anticipating the full 60 minutes. Surgical supplies were covered, and the OR was supplied with chairs, tissues, and soft music. CM was extubated in the OR, and circulatory death occurred after ten minutes. His liver and cardiac valves were donated, and his brain was bequeathed for autism research, honoring his parents' wishes to help other children and families.

**Conclusion:** A paucity of literature exists regarding the role of pediatric PC during DCD. This case illustrates one way for interdisciplinary PC teams to support and collaborate with families and medical teams pursuing DCD.

### ***Is There a Role for Autopsy in Palliative Care? (TH332B)***

Jessica Goldberg, NP, Memorial Sloan Kettering Cancer Center, New York, NY

Stacy Stabler, MD PhD, Memorial Sloan Kettering Cancer Center, New York, NY

#### **Objectives**

- Describe the benefits of autopsy.
- Identify role of Palliative Medicine team in the autopsy consent discussion.

**Background:** Over the last 75 years, the rates of autopsy have drastically declined, and today less than 5% of patients undergo an autopsy. The numerous benefits of autopsy include the advancement of basic science and clinical research, improvement of medical education, and possible contributions to family and patient well-being.

**Case Description:** A 37-year-old male with newly diagnosed diffuse large B-cell lymphoma presented to the emergency department complaining of fever and headache and was admitted for management of neutropenic fever of unknown origin. Three days after admission, the patient developed slurred speech and word finding difficulties. The results of a lumbar puncture were nonspecific. The patient subsequently developed progressive altered mentation and was transferred to the intensive care unit, where he was intubated the following day. One week after admission, the PCR testing of cerebrospinal fluid demonstrated West Nile Virus. Palliative Medicine was consulted, and during a family meeting, the medical team requested consent for an autopsy. The patient's family had difficulty assenting due to concerns over religion, timing, autonomy, and a desire to honor their son's life. Over a period of days, the interdisciplinary palliative medicine team met repeatedly with the family to explore these issues, and the family ultimately consented to a limited autopsy.

**Conclusion:** Research has demonstrated that the clinician's level of knowledge and attitude towards autopsy are the biggest factors which determine whether the procedure will be discussed and consented. The pediatric oncology literature suggests that autopsy should be included in the discussion regarding patients' preferences and goals at end of life. The autopsy consent conversation should be individualized to the family, be sensitive to religious and cultural concerns, and should involve practitioners from multiple disciplines.

## ***Palliative Care in Transplant Surgery (TH332C)***

Michael Aref, MD PhD FACP FHM, Indiana University Health, Indianapolis, IN  
Jonathan Fridell, MD, Indiana University School of Medicine, Indianapolis, IN

### **Objectives**

- Identify and address similarities and differences in delivery of care between transplant surgery and palliative care
- Applying palliative care communication skills to providers and using symptom management knowledge to improve care to grow opportunities for alleviation of suffering
- Demonstrating tools for educating other providers of the benefits of suffering management provided by specialty palliative care

**Background:** Transplant surgery seeks to improve patient's quality of life by surgically providing a healthy organ to replace a diseased one. As with any complex surgery, some patients present with co-morbidities that worsen symptom burden or have courses with increased symptom burden.

**Case Description:** A 34 year male with history of brittle diabetes mellitus status-post pancreas transplant complicated by bowel obstruction due to adhesions, perioperative myocardial infarction, depression with anxiety, and post-traumatic stress disorder. The patient was medically stable for discharge yet had persistent abdominal pain and nausea. He felt he was needed at work and was not fulfilling his role as a father due to his illness and complications. Following palliative care consultation, the patient's abdominal pain was controlled with pregabalin, topical lidocaine, and trigger point injections to his incision. Nausea was refractory to multiple first-line anti-emetics. It was managed using a multifactorial approach for anxiety, food aversion, and medication-associated nausea. Primary mood and anxiety disorders were treated by cognitive behavioral therapy as well as switching him from an SSRI to venlafaxine and mirtazapine. His nausea improved dramatically with scheduled low-dose dronabinol and he was discharge three days later. He has been readmitted twice, the first time four months after palliative care referral for conservatively managed small bowel obstruction and a month later for cytomegalovirus enteritis, but otherwise has returned to an improved baseline in both his work and family life.

**Conclusion:** This case demonstrates the need for palliative care in transplant patients to help improve their quality of life, decrease readmission rates, and length of stay. Rather than palliative care being a marker of increased mortality, palliative care consultation may actually decrease morbidity and mortality rates.

## ***Designing a Detailed Plan for Discontinuation of a Left Ventricular Assist Device (LVAD) in the Home Hospice Setting (TH362A)***

Joan Panke, MA NP ACHPN, MedStar Washington Hospital Center, Washington, DC

Hunter Groninger, MD FACP FAAHPM, MedStar Washington Hospital Center, Washington, DC

Renee Holder, PharmD BCPS CPE, MedStar Washington Hospital Center, Washington, DC

Anne Kelemen, MSW, MedStar Washington Hospital Center, Washington, DC

### **Objectives**

- Describe steps needed to transition a patient with an LVAD from hospital to home hospice
- Outline steps and key issues to address/document in the decision making process for device deactivation
- Design a specific protocol for LVAD deactivation that considers the device mechanics and hemodynamic changes

**Background:** As more individuals elect LVADs to support cardiac output, palliative care and hospice providers require increasing knowledge and skill to care those living and dying with MCS devices. For many in terminal stages of illness, home is still the preferred site of death. To our knowledge, cases that provide specific steps for LVAD transfer to home hospice and step by step protocols for decision making and deactivation have yet to be described.

**Case description:** VJ was a 66-year-old man with ischemic cardiomyopathy who had an LVAD implanted for worsening functional decline. His prolonged hospital course was complicated by bleeding, strokes, respiratory failure, and neurocognitive decline. Palliative care facilitated multiple family meetings to address evolving prognosis. Eventually, the decision was made to elect home hospice. Prior to discharge, family education required close collaboration between the heart failure and palliative care teams, nursing, case management and the hospice, and a clear interdisciplinary plan improved efficiency of the transfer home. When the decision to deactivate the device was being considered, a list of important considerations was created and key issues documented across settings. Finally, the a protocol was created that spoke to the mechanics of LVAD deactivation, taking into consideration all aspects of the process and the unique symptom needs given the effect on hemodynamics post-deactivation.

**Conclusion:** This case provides providers with specific protocols for patients choosing to deactivate LVADs in the home hospice setting.

## ***Anticipation of Post-Extubation Stridor, Dyspnea and Distress After Terminal Ventilator Withdrawal (TH362B)***

Gretchen Jones, DO, Providence Alaska Medical Center, Anchorage, AK  
Tram Chu, MD, Providence Alaska Medical Center, Anchorage, AK  
Ursula McVeigh, MD, Providence Alaska Medical Center, Anchorage, AK

### **Objectives**

- Recognize patients at risk for post-extubation dyspnea, stridor and distress
- Describe evidence-based tools (including Respiratory Distress Observation Scale—Campbell, et al 2010) to aid in determination and anticipation of post-extubation stridor
- Describe bedside interdisciplinary team support and communication with the family and loved ones of the patient during terminal ventilator withdrawal

**Background:** As a Palliative Care team caring for critically ill patients in the ICU, care plans often include terminal ventilator withdrawal during which we strive to assure patient comfort and family support. Distressing symptoms after extubation could include dyspnea, stridor and subsequent respiratory distress. This may also cause turmoil across the care team at the bedside. This case demonstrates post-extubation distress with review of measurements that may have been utilized to anticipate this event.

**Case Description:** A 64 year-old male admitted for acute large left MCA stroke with subsequent respiratory failure requiring intubation. History includes HTN and suspicion of OSA. Wife conveys patient's wishes of no prolonged life support if poor prognosis/neurological outcome. By day #11 he had minimal neurologic improvement with a dense right hemiplegia, receptive and expressive aphasia, opening of the eyes, purposeful movement to the LUE but not following commands and developed a pneumonia, with intermittent copious secretions requiring three bronchoscopies (with trachea/bronchomalacia). Goals of care were delineated to prioritize comfort along with aim for life-extension without burdensome therapies. Plan was to extubate with medical management, but if respiratory failure, no re-intubation and transition to comfort end-of-life care. After extubation, patient exhibited stridor, dyspnea and anxiety with resultant patient, family and staff distress during period of medication titration. Racemic epinephrine, opioids, benzodiazepines titrated for comfort. The patient's wife was supported at the bedside by Palliative Care staff, chaplain and ICU nursing staff. Comfort achieved, and patient passed peacefully several hours later.

**Conclusion:** Preparing for all eventualities following extubation of a seriously ill patient can be difficult. Our team has been researching published tools that may aid in anticipation of stridor, one such tool is the



Respiratory Distress Observation Scale (Campbell, 2010). Communication and preparation with family before terminal extubation with bedside support is essential to quality end-of-life care.

## ***Compassionate Extubation in Super Refractory Convulsive Status Epilepticus: Applying the Principle of Proportionality (TH362C)***

Sam Maiser, MD, Medical College of Wisconsin, Milwaukee, WI  
Hannah Hall, MD, University of Minnesota, Minneapolis, MN  
Jeffrey Rubins, MD, Hennepin Health Service, Minneapolis, MN

### **Objectives**

- Describe counseling strategies when recommending cessation of life-sustaining treatment in the setting of super refractory convulsive status epilepticus caused by severe anoxic injury.
- Discuss the pros and cons of continuing lethal sedation when performing compassionate extubation.

**Background:** Compassionate extubation is used to relieve the suffering of mechanically ventilated patients whose wishes are consistent with stopping life-sustaining treatments. The process involves stopping the ventilator, withdrawing the endotracheal tube, and providing symptomatic treatment until death. Experienced medical providers should be present to ensure proper alleviation of symptoms. Typically, medications such as propofol are not used for sedation during compassionate extubation, to minimize risk of hastening death. Super refractory status epilepticus (SRSE) is defined as SE that continues or recurs 24 hours or more after the onset of anesthetic therapy. The purpose of this case is to demonstrate the importance of the principle of proportionality when considering sedation during compassionate extubation in a patient with SRSE.

**Case Description:** A 43 year-old female suffered acute hypoxic respiratory failure that resulted in cardiac arrest and severe anoxic encephalopathy. Following cardiopulmonary resuscitation, the patient developed convulsive SE within 24 hours. She was treated with four anticonvulsants (phenytoin, valproic acid, levetiracetam, and lacosamide), propofol infusion at 80 mg/hr, and a midazolam infusion at 50 mg/hr. Despite these treatments, she continued to have convulsions for 26 days. Unfortunately, she had no chance of meaningful neurologic recovery, and with the help of the palliative medicine team in discussions with her surrogates, she was transitioned to a comfort plan of care. The need to continue deep sedation with propofol and midazolam to minimize suffering from seizures during dying was discussed, and the decision was made to continue them upon extubation despite the possibility that these treatments could hasten the patient's death. This choice was deemed ethically appropriate because the intention was to avoid recurrence of convulsions and minimize family distress.

**Conclusions:** The principle of proportionality would justify the continuation of deep sedation following extubation when the intention of the sedation is to prevent convulsions.



## ***Challenges, Successes and the Unexpected in the Management of a High-Grade Malignant Bowel Obstruction (FR421A)***

Erica Leonard, MD, University of Alabama at Birmingham, Birmingham, AL

Keith Swetz, MD MA FACP FAAHPM, University of Alabama at Birmingham, Birmingham, AL

### **Objectives**

- Explore challenges to the management of a malignant high-grade bowel obstruction in patients who are not surgical candidates.
- Review adjunctive approaches to refractory pain when pain-sedation mismatch occur, and when the enteral route is limited.
- Discuss approaches to shared decision-making in optimizing patient-centered outcomes in the above setting.

**Background:** Malignant small bowel obstruction (MSBO) occurs in 3-15% of patients with cancer. Optimizing quality of life (QOL) is crucial in non-operative patients, as mean survival is <4 weeks. Established approaches exist but not all patients benefit from nasogastric decompression or can receive venting gastrostomy. Furthermore, MSBO or venting may impair optimal pain management eternally.

**Case Description:** A 47 year-old man with metastatic rectal carcinoma presented with abdominal pain and absent colostomy output for 14 days. Computerized tomogram confirmed high-grade MSBO with three distinct transitions points. Surgery was not offered. Symptoms were managed with nasogastric decompression, parenteral hydromorphone, octreotide and dexamethasone. Patient desired to eat for QOL, and did so with nasogastric tube to suction. Intravenous nutrition/hydration were avoided given significant third-spacing. Venting gastrostomy was attempted, but not feasible with fixed overlying bowel, and substantial intragastric retained food despite suction. Regardless, patient opted to eat as tolerated for QOL.

Pain management was challenging. Escalating opioids helped little and worsened sedation. Given enteral limitations, intravenous lidocaine was initiated and was highly effective in reducing pain and pain-sedation mismatch.

Three weeks into hospitalization, patient displayed progressive asthenia, cachexia, and renal failure from malignant ureteral compression. The patient seemed at peace with dying in the hospital. However, he spontaneously had intermittent colostomy output, improved urinary output and tolerance of nasogastric clamping despite radiographic progression of MSBO noted on hospital day 38. Patient was discharged on

hospital day 43 without nasogastric tube, with ongoing parenteral hydromorphone, lidocaine, dexamethasone and octreotide. He continues on actively coordinated home hospice care now >100 days post-presentation.

**Conclusion:** MSBO is a dynamic process that requires a thoughtful, flexible approach. For some patients, morbidity and mortality may not correlate well with radiographic findings. Careful, regular exploration of goals of care is necessary to optimize patient-centered outcomes.

## ***Atypical Pain Management for a Patient with Hypertrophic Osteoarthropathy and Advanced Lung Cancer (FR421B)***

Kristina Newport, MD FAAHPM, Hospice & Community Care, Lancaster, PA

Kathryn Heinzl, MS, APC, Lancaster, PA

Shanthi Sivendran, MD, Lancaster General Health, Lancaster, PA

### **Objectives**

- Understand the unique characteristics of HPOA and effect on cancer management
- Identify potential psychosocial factors that affect pain from conditions such as HPOA
- Understand the method of sandostatin use for treatment of HPOA
- #1, #2, and #3

**Background:** Hypertrophic osteoarthropathy (HPOA) is a rare but potentially debilitating condition experienced by patients with lung cancer and other diseases with pulmonary involvement. Two case reports suggest sandostatin may be effective in treating pain due to HPOA, but neither patient survived long enough to assess appropriate dosing or long term effects. We describe a case of a patient who had dramatic, durable response to sandostatin.

**Case Description:** Our patient is a 62 year old female with a history of adenocarcinoma of the lung and four years of debilitating pain in the bilateral lower extremities due to HPOA. Upon palliative consultation she had been intolerant or refractory to acetaminophen, dexamethasone, diclofenac, duloxetine, gabapentin, ketorolac, zoledronic acid and methylprednisolone. She had tried morphine, fentanyl, hydromorphone oxycodone and methadone, requiring q6 month opioid rotations. She was hospitalized multiple times for refractory pain and limited her ambulation due to pain. She had a high level of anxiety, was skeptical of new treatments and frustrated by multiple ineffective attempts to treat her condition. After a joint visit with a Palliative Medicine physician and Chaplain, she agreed to trial sandostatin. Based on limited case reports, she was started on sandostatin, 100mcg subcutaneous injection daily for 14 days. She had complete resolution of her lower extremity pain and was able to discontinue her breakthrough hydromorphone and wean her methadone dose. Her improved pain control and ongoing spiritual support facilitated improved function and tolerance of ongoing cancer treatment.

**Conclusion:** Sandostatin is a tolerable intervention to treat HPOA associated with active lung cancer. Patients with refractory pain due to HPOA should be offered this treatment, in the setting of comprehensive psychosocial support, as a method of treating refractory pain.

## ***Gabapentin—Jack of All Trades (FR421C)***

Monika Holbein, MD, West Virginia University, Morgantown, WV

Jennifer Pruskowski, PharmD, University of Pittsburgh School of Pharmacy, Pittsburgh, PA

### **Objectives**

- To identify the prevalence and significance of delirium in Parkinson's Disease and patients with underlying dementia
- To review typical and atypical pharmacological options for the management of delirium
- Review gabapentin's pharmacology, safety considerations, potential adverse drug reactions, and cost and compare these parameters to typical pharmacological options for delirium

**Background:** Delirium in patients with Parkinson's Disease is a challenging clinical situation. Traditional pharmacological options are relatively contraindicated in Parkinson's Disease due to antidopaminergic effects. This presents a challenge for palliative care as delirium inhibits quality of life and meaningful interactions. Gabapentin has been hypothesized as an option for this population.

**Case Description:** DS is a 64 year old man with Parkinson's Disease, dementia, hydrocephalus and multiple falls. He presented from his nursing home with multiple intracranial bleeding processes after a fall. He was treated conservatively and nursing home medications were continued including carbidopa-levodopa and clonazepam. On day 3 of admission the consult was for goals of care clarification was placed by primary team. He was found to be unresponsive, in restraints secondary to agitation, requiring nasogastric tube for access. Delirium was diagnosed using the CAM-ICU. The plan was made to focus on comfort and treat his delirium. Deliriogenic medications including clonazepam were discontinued. Non-pharmacologic modalities were initiated. That night he had increased agitation. He received two doses of haloperidol overnight. Despite becoming more alert and able to take oral medications, it was feared that haloperidol would exacerbate his Parkinson's Disease. Gabapentin has been shown to reduce post-operative delirium in older patients. Gabapentin was initiated at 300mg by mouth three times daily. After two doses he was able to sleep without episodes of agitation. In the morning he was more interactive and his mental status was at baseline. Gabapentin was continued in nursing home. His wife wanted to wait until the patient was settled to involve hospice.

**Conclusion:** Delirium is a challenging symptom since threatens quality of life and meaningful interactions. Conventional pharmacological agents for delirium are typically inappropriate for patients with Parkinson's disease. Gabapentin is a promising agent for this population. Additional research is needed to explore the use of gabapentin in delirium.

## ***"Comfort Care" Planning for Individuals with Developmental Disabilities: The Importance of Following Your State's Mandatory Procedures When Creating a Plan that Includes Withholding or Withdrawing Life Sustaining Treatment (FR422A)***

Mary Feeley, ACHPN ANP, Maimonides Medical Center, Brooklyn, NY

Stuart Kaufer, MSW, Maimonides Medical Center, Brooklyn, NY

Tzvetelina Voynova, MD, Maimonides Medical Center, Brooklyn, NY

### **Objectives**

- Describe 3 or more patient characteristics that inform the need to apply special precautions when using surrogate decision making to withhold or withdraw life sustaining therapy
- Explain 3 or more specific procedures established by state regulations the medical team must follow when using family decision makers for persons with developmental disabilities
- Identify at least 3 underlying illnesses or conditions that should be present in a patient being considered for "comfort care"

**Background:** A referral for "comfort care" was received for a patient admitted with aspiration pneumonia 9 days prior to a large, urban teaching hospital. The history provided was: middle aged patient with Down's Syndrome, living in a state authorized group home, the sibling is a surrogate decision maker. The sibling consented to Do Not Resuscitate and Do Not Intubate (DNR/DNI) for the patient earlier during this hospitalization. Almost simultaneously to our receipt of the consult request, the patient developed respiratory failure and required intubation and mechanical ventilation.

**Case Description:** Search of hospital chart did not reveal the requisite documents a protected class citizen must have in the medical record, such as guardianship paperwork, health care proxy, Mental Hygiene Legal Services contact. At the time of establishing DNR/DNI, several senior staff reviewed and commented on the patient's care including an attending psychiatrist, internal medicine attending physician, social worker, case management staff, hospital administrator, several resident physicians, and nursing staff who participated in the care. The request for "comfort care" to be established for patients without capacity who receive care through the state office for persons with developmental disabilities must be done according to regulations that have been established by the state. This also applies to withholding or withdrawing life sustaining treatments including DNR/DNI. An immediate call to hospital administration and to the NY state office for Persons with Developmental Disabilities informed the need to reverse the DNR/ DNI until the proper safeguards were complied with. The unfortunate occurrence of the respiratory failure shortly afterward further complicated our relationship with the family.



**Conclusion:** In order to lawfully establish a plan of care that includes withholding or withdrawing Life Sustaining Treatment for an individual with a development disability the state mandatory safeguards must followed.

## ***When Caregiver Fatigue Affects Surrogate Decision-making for the Seriously Ill Patient (FR422B)***

Christopher Lawton, MD, Icahn School of Medicine at Mount Sinai, New York, NY

Noelle Marie Javier, MD, Icahn School of Medicine at Mount Sinai, New York, NY

Terry Altilio, LCSW, Icahn School of Medicine at Mount Sinai and Beth Israel Deaconess Medical Center, New York, NY

### **Objectives**

- Describe how caregiver fatigue serves as a potential barrier to effective surrogate decision-making for a loved-one with serious illness
- List three mechanisms by which an effective palliative care team can help overcome this barrier and mediate future emotional and psychological trauma for surrogates

**Background:** The burden of caregiving is significant. Approximately 10% of caregivers experience effects on physical health and up to 70% experience depressive symptoms. Caregiver fatigue can affect the ability to serve as a surrogate decision-maker and can lead to many forms of conflict.

**Case Description:** An 83 year old man presents with myocardial infarction and cardiogenic shock. The patient's daughter who acts as primary caregiver and surrogate decision maker elects, with the medical team's support, for palliative extubation. On the morning of the planned procedure the team finds the patient clinically improving and recommends holding off on extubation and continuing current therapies with the ultimate goal of extubation. The daughter insists on immediate removal of the breathing tube, citing the burden and exhaustion felt as caregiver. This sentiment leads to questioning of her motivations. With rising moral distress, the team calls an emergent ethics consultation and immediate follow-up by palliative care. During the family meeting, the daughter becomes tearful, shares her physical and emotional fatigue and overwhelming stress as decision-maker. In the setting of non-judgmental and empathetic communication with both teams, she becomes empowered to continue current therapies with the ultimate goal of extubation based on her knowledge of her father's wishes and in light of ongoing clinical improvement. This mediation obviated the need for ethics consultation. The timely involvement of palliative care created a space for all viewpoints to be heard and respected, allowed the daughter to explore her father's values, and facilitated agreement on a treatment plan consistent with those values. The patient is extubated the following day and continues to improve.

**Conclusion:** This case demonstrates the impact of caregiver fatigue on surrogate decision-making and the effective use of palliative care through open discussion, conflict mediation, and formulation of an appropriate treatment plan based on mutually agreed goals.

## ***Symptoms, Surrogates, and Statutes: The Slippery Slope of Pain Management, End-of-life Decision Making, and DNR Laws in Pregnant Women (FR422C)***

Jill Ann Jarrell, MD MPH, Texas Children's Hospital, Houston, TX

Leah Greene, JD LLM, Kroger | Burrus, Houston, TX

### **Objectives**

- Be able to enumerate palliative care and ethical issues that are unique to obstetrics.
- Understand discrepancies in laws pertaining to obtaining and implementing DNR orders in pregnant patients.

**Background:** Palliative care in obstetrics is not well defined given its infrequent use; however, obstetric palliative care issues are unique and complex. DNR laws for pregnant patients are not consistent throughout the United States and often times do not allow for optimum palliation.

**Case Description:** A 30 year old woman was diagnosed with stage 4 breast cancer at 8 weeks gestation of a singleton intrauterine pregnancy. At the time of diagnosis, she told her obstetrician that she wanted to proceed with the pregnancy and keep the baby as healthy as possible. The patient's disease progressed rapidly with metastases to the brain and to the bone causing encephalopathy and severe pain. At 22 weeks gestation, the patient stated that she wanted aggressive symptom management and to be DNR and then lost decision making ability shortly thereafter. Her mother attempted to execute the patient's wishes; however, a DNR is illegal in Texas for pregnant patients and the primary service was uncomfortable with aggressive use of narcotics given the fetus was on the cusp of viability. An interdisciplinary team was gathered consisting of the patient's mother, obstetrics, neonatology, palliative care, ethics, chaplaincy, social work, risk management, and nursing to develop a plan of care that was patient-centered, consistent with medical bioethical standards, and compliant with state law. The patient and the fetus died at 24 weeks of gestation after having received narcotics for pain control, anti-psychotics for agitation control, but after having endured two rounds of cardiopulmonary resuscitation for cardiac arrest.

**Conclusion:** Providing effective palliative care in pregnant patients is exquisitely difficult given the myriad of medical, social, ethical, spiritual, and legal issues that are involved and requires an interdisciplinary team for guidance and implementation. Further research and advocacy is needed to ensure state laws permit proper palliation in pregnancy.

## ***To Be or Not To Be: Suicidality and Voluntarily Stopping Eating and Drinking At the End of Life (FR442A)***

Joshua Briscoe, MD, Duke & VA Medical Center, Durham, NC

### **Objectives**

- Use criteria for decision-making capacity to distinguish between suicidal ideation that warrants psychiatric intervention and a desire to cease medical intervention.
- Identify relevant ethical factors in assessing patients who express a wish to die.
- Identify significant intersections of hospice and palliative medicine (HPM) and mental health care.

**Background:** Suffering may manifest itself as intractable demoralization that is voiced by the patient as an unwillingness to continue to live. Requests to stop treatment or to refuse nutrition may not signal overt suicidal ideation, but rather ambivalence about a patient's present state; if symptoms could be better controlled, the desire to die may diminish or be eliminated entirely. Although decision-making capacity is important to determine in these cases, it is also important to understand the motivation behind the patient's requests.

**Case Description:** A 63 year old woman presented from a skilled nursing facility (SNF) to the inpatient medicine service with recurrent melena from ANCA-positive vasculitis, diagnosed three months prior in the setting of a myocardial infarction. During her latest admission, she reported that, given the uncertainty of her prognosis and burden of symptoms, she would refuse treatment as well as nutrition.

The psychiatry service was consulted to help determine the patient's decision-making capacity to refuse these interventions. Her desire to stop nutrition was not a wish to die, but rather to avoid symptoms caused by nutritional intake. Given the clarity and continuity of thought over years, and lack of overt suicidal ideation, we determined she did not have impaired judgment. Since the patient was requesting hospice and did have significant symptoms, palliative care was consulted. All interventions were stopped but the patient's symptoms improved to the point that she decided to return to the SNF upon discharge.

**Conclusion:** This case examines ethical dilemmas pertaining to psychiatric assessment that may arise at the end of life regarding cessation of medical interventions and nutrition. These involve concerns regarding patient agency, provision of compassionate and beneficent care, decision-making capacity, suicidality assessment, and adequate assessment of goals of care. Interventions may impose their own symptom burden that, when removed, allow for improvement in quality of life.

## ***Hunger Games: Balancing Benevolent Coercion and Informed Refusal in the Setting of Terminal Anorexia Nervosa (FR442B)***

Jason Morrow, MD, PhD, University Health System; UT HSC San Antonio, Boerne, TX

### **Objectives**

- Recognize the key diagnostic criteria, evidence-based management guidelines, and interdisciplinary support strategies for Anorexia Nervosa that are relevant to Hospice and Palliative Care clinicians.
- Identify and apply the elements of informed consent, informed refusal, and capacity assessment as they apply to life-and-death decisions and mental illness.
- Evaluate ethical justifications for and limitations on benevolent coercion for Hospice and Palliative Medicine clinicians.

**Background:** Anorexia Nervosa (AN) can impair decisional capacity while also reflecting personal choice, preferences, and values. Diagnosis and management of refractory AN involves complex capacity assessments and struggles over bodily control. Clinicians can face a challenging and dramatic choice: benevolent coercion with invasive life-sustaining treatments or acquiescence to the stated wishes of a patient who may not possess decisional capacity regarding a traditionally non-terminal mental illness.

**Case Description:** Ann R. is a 28 year-old woman with refractory AN, having struggled with life-threatening weight loss and repeated hospitalizations since her teenage years. Ann recently completed a second intensive, 3-month inpatient treatment at a specialized center. Within weeks, Ann relapsed and was admitted to the hospital. TPN was started along with strict dietary and behavioral restrictions. Daily assessment was complicated by what Ann's therapist described as “manipulative” negotiations. Ann soon vocally objected to ongoing treatment, occasionally biting at her nurses and pulling out her IV access. A 1:1 sitter was provided along with physical and chemical restraints. Over a period of weeks, Ann received support from the Palliative Care team, routine psychological counseling, and a trial of ketamine infusion. She subsequently announced that she wanted no further treatment and would rather die than be “a prisoner.” A psychiatry evaluation and court order declared that Ann had the capacity and competency to make medical decisions. Ann was discharged home with hospice support.

**Conclusion:** The case of Ann R. demonstrates the challenges of diagnosing and managing refractory AN. Patients cannot be held or treated indefinitely against their will if they are deemed capacitated and competent. However, effective management of AN always requires sustained, interdisciplinary support, and careful

negotiation. The ethical contours of benevolent coercion include an account of the limits of traditional capacity assessments for AN and when AN is refractory or terminal.

## ***Intermittent Palliative Sedation: Taking a Break from Symptoms at End-of-Life (FR442C)***

Sudha Natarajan, PhD NP, Massachusetts General Hospital, Boston, MA

### **Objectives**

- Contrast intermittent palliative sedation (IPS) with palliative sedation until death in patients with intractable symptoms
- Review relevant data describing the indications for, use and risks/benefits of IPS
- Identify patients who may derive benefit from IPS

**Background:** Intermittent palliative sedation is an understudied, yet potentially beneficial intervention for management of intractable symptoms in patients with advanced disease.

**Case Description:** Mr. G is a 71 year old man with a history of metastatic castration-resistant prostate cancer with extensive bony involvement, who suffers from escalating back/bone pain. During periods of good pain control, Mr. G enjoys meeting friends at his local pub and dining with his wife. He was recently admitted in pain crisis, which persisted despite methadone PCA, oral ketamine, dexamethasone and intravenous fentanyl boluses at the bedside. Palliative sedation was discussed; however, prior to initiation, Mr. G became sedated with a fentanyl infusion and scheduled intravenous lorazepam for approximately 24hrs, after which he roused briefly and verbalized his pain was well-controlled. Given this apparent improvement, his regimen was reduced and he became more alert with sustained analgesia. His pain regimen was significantly down-titrated and he was able to ambulate with a walker within 3 days.

Palliative sedation (PS) is most often used in patients who experience intractable symptoms at end-of-life and commonly refers to continuous sedation until death. Intermittent palliative sedation (IPS), or respite sedation, involves sedation for a predetermined time, then lightening of sedation to assess symptoms. Limited case reports suggest that IPS may break the cycle of intractable symptoms and psychological distress, lessening symptoms while the patient is awake and improving quality of life. Unlike PS, no robust data describe the methodology, indications for, or outcomes of, IPS. We will examine prior reports of IPS, potential risks/benefits and consider patients who may benefit.

**Conclusion:** Many patients with advanced disease suffer from intractable symptoms significantly impairing quality of life. Although IPS was not the intended intervention for Mr. G, this case highlights the potential benefit of IPS. Palliative care clinicians should be aware of this potentially beneficial intervention.

## ***Palliative and End of Life Care for an Arabic Muslim Boy with Osteosarcoma (FR462A)***

Rachel Thienprayoon, MD, Cincinnati Children's Hospital Medical Center, Cincinnati, OH

Mark Meyer, MD, Cincinnati Children's Hospital, Cincinnati, OH

Hilary Flint, DO, Cincinnati Children's Hospital Medical Center, Cincinnati, OH

### **Objectives**

- Discuss the ethical challenges raised when parents do not disclose prognosis to their children.
- Recognize cultural differences in discussions around end-of-life care and DNR for Arabic, Muslim families.
- Discuss systems issues of caring for a child who is acutely decompensating on an oncology unit without a Do-Not-Resuscitate order.

**Background:** Many children's hospitals have seen an influx of international patients, particularly from the Middle East. Caring for international patients can present unique cultural and ethical challenges, which may be exaggerated at the end of life.

**Case Description:** O. was a 13 year male with osteosarcoma of the right femur who presented from Saudi Arabia in 2013. Sadly, he relapsed locally in early 2015 and distantly to his lungs in May. His course was complicated by obsessive-compulsive disorder, significant behavioral issues, and a language barrier; his primary language was Arabic. Parents would not allow the care team to discuss his terminal prognosis with O, or allow interpreters to interpret discussions between O and his parents to providers. During his last week of his life, also Ramadan, he developed severe dyspnea. A chest x-ray revealed a massive tension pneumothorax. His mother wanted him to remain on the floor, but would not consent to placing a "DNR" order. She wanted to make decisions for O in "real-time" and recognized his greater comfort in this familiar environment. This raised issues around ethics: parental decision-making and honesty with O about his imminent death; safety: nursing discomfort in "ignoring" warnings prompting them to take action in the EMR, and systems: whether and when to transfer him to the intensive care unit. Representatives from oncology, palliative care, ethics, hospital safety, the intensive care unit, an interpreter, and O's mother met mother several times that day. Ultimately, after prayer, she consented to placing a DNR order and allowed us to focus on O's comfort. He died peacefully three days later.

**Conclusion:** A multidisciplinary approach that involved ethics, palliative care, nursing leadership, oncology and the hospital safety officer were able address complex ethical and cultural challenges surrounding this patient's death.



## ***Mortality Associated with “Fixable” Hemorrhage in the Face of Serious Underlying Illness: Interdisciplinary Strategies for Helping Providers Cope (FR462B)***

Ana Berlin, MD, MPH, Rutgers - New Jersey Medical School, Newark, NJ

Anne Sutherland, MD, Rutgers – New Jersey Medical School, Newark, NJ

Susanne Walther, APRN, University Hospital, Montclair, NJ

### **Objectives**

- Identify factors that contribute to clinicians’ moral distress associated with life-threatening hemorrhage from focal lesions ordinarily perceived as “fixable.”
- Outline how interdisciplinary perspectives can help refocus care on the patient’s dignity and comfort and reframe hemorrhage as an aspect of the overall deterioration of the patient.
- List evidence-based best practices for supporting patients and families facing terminal hemorrhage in the acute hospital setting.
- Describe how structured debriefing can help clinicians process moral distress and prepare for future encounters where rescue of a bleeding patient may not be in keeping with goal-directed care.

**Background:** Terminal illness may result in death via several mechanisms, including hemorrhage. While the hospice literature helps patients and families prepare for terminal hemorrhage outside the hospital, hemorrhage is rarely viewed as an acceptable terminal event in the acute care setting. This bias leads to a perceived imperative to rescue the bleeding patient, and may drive aggressive interventions incongruent with the patient’s goals.

**Case Description:** Two patients presented with life-threatening hemorrhage from focal anal lesions. One was a 29-year-old admitted with acute alcoholic hepatitis and encephalopathy. After 30 days in the intensive care unit with multiple bouts of sepsis and multisystem organ failure, dislodgment of a fecal containment system produced hemodynamically significant hemorrhage from an anal ulcer in the presence of portal hypertension. Although the hemorrhage was temporized, low-grade bleeding continued. Ongoing interdisciplinary discussions with the patient and his family led to cessation of aggressive resuscitative measures and renal replacement therapy. The patient was allowed to eat for the first time in weeks, and died comfortably with family at bedside.

Another patient was a 39-year-old with AIDS dementia admitted with hemodynamically significant bleeding from a focal anal lesion. Workup revealed widespread malignancy. Topical hemostatic agents and anal canal tamponade controlled the bleeding. After discussion with her family, and with their support, the patient was discharged to hospice, with preparation for recurrent bleeding, to be treated as a terminal event.

**Conclusion:** Exsanguinating hemorrhage in patients with serious underlying illness is distressing, but not an illegitimate pathway to dying. Interdisciplinary approaches and structured debriefing can help providers cope with the sense of failure associated with inability to rescue the seriously ill bleeding patient. Reframing success in terms of tending to the comfort and palliative care needs of patients can help clinicians achieve peace with a potentially distressing mode of death.

## ***A Model of Collaboration between Oncology Interdisciplinary Team Members and Outpatient and Home Based Palliative Care in an Urban Academic Medical Center (FR462C)***

Allison Stark, MD MBA, Montefiore Medical Center, Bronx, NY

Marlene McHugh, DNP FNP ACHPN FPCN, Montefiore Medical Center, Bronx, NY

Sarah Stapleton, LCSW, Montefiore Medical Center, Bronx, NY

Elizabeth Colkin Clarke, LCSW, Montefiore Medical Center, Bronx, NY

Roxanne O'Brien, RN, Montefiore Medical Center, Bronx, NY

### **Objectives**

- Define key elements of intensive case management for palliative patients.
- Describe performance metrics of intensive case management for palliative patients.

**Background:** Montefiore Medical Center is an academic medical center located in an urban underserved area of the Bronx. Montefiore's cancer center is an NCI designated site with multiple locations and approximately 17,000 annual visits per site. The palliative care service has had a presence in the oncology clinic since 2004. As the need for palliative care services expands across the health care continuum, efforts are underway to optimize the transitions of care with a global focus on the medical, social and psychosocial needs of our patients. Our aim is to enhance communication across disciplines as a way to achieve patient and family centered goals and maximize quality of life throughout the treatment process.

**Case Description:** We have identified three patient cases involving cancer patients with complex psychosocial needs and multiple barriers to care who were managed over a six to twelve month period of time. We will present them through a qualitative and quantitative lens and will illustrate how collaboration between outpatient oncology, outpatient and home based palliative care, and telephonic care management enhances the quality of life of patients and families with complex symptom distress and psychosocial issues. The collaboration between inpatient and outpatient specialist and generalist teams served as an example of an alternative care delivery system for patients and families not enrolled in hospice based on medical criteria or patient choice. Intensive care management between multiple teams improved quality of life for patients and families while simultaneously decreasing hospitalizations and readmissions.

**Conclusion:** Within one medical center, a team of multidisciplinary clinicians across care settings can collaborate, communicate and manage patients and families with complex medical and psychosocial needs in an urban underserved population in order to reduce symptom distress.

## ***An Interdisciplinary Approach to Dialysis Decision-Making for the Critically Ill “Un-befriended” Patient (SA518A)***

Jennifer Scherer, MD, New York University School of Medicine, New York, NY

Aprajita Mattoo, MD, New York University, New York, NY

### **Objectives**

- To apply bioethical principals to the care of the “un-befriended” patient with kidney disease.
- To design a framework for dialysis decision-making for the “un-befriended” patient.
- To learn how to utilize interdisciplinary teams (IDT) when caring for a critically ill patient with AKI.

**Background:** The un-befriended patient is one that lacks decision-making capacity and a surrogate decision-maker (SDM). Nephrologists encounter unbefriended patients often, yet limited literature exists to guide renal decision-making for these vulnerable patients. This case describes an inter-disciplinary approach to caring for a critically ill “un-befriended” patient.

**Case Description:** Mr. S was 74 year old male wheelchair bound nursing home resident who underwent an urgent right hemicolectomy for a perforated colon. His post-operative course was complicated by septic shock and multi-organ failure including AKI secondary to ATN. During this time his creatinine increased from 0.8 to 3.6 mg/dl, with urine output of < 500cc/day. Mr. S was obtunded and had diffuse anasarca. He lacked advance directives and any SDM. The SICU believed that dialysis should be withheld given his poor prognosis and quality of life (QOL). The four-topic approach to ethical decision-making was applied (Figure 1). Under provisions of the NY State Family Health Care Decisions Act (FHCDA), an estranged sister (who declined to be a SDM) was asked to partake in an IDT family meeting with renal, palliative care, bioethics, and the SICU to explore the patient’s values. It was establish that Mr. S cherished his life in the NH. Given this information, the renal team decided that a time-limited trial of dialysis would be reasonable. His AKI was potentially reversible and he would value a life in a NH, even with dialysis. Before dialysis was needed, Mr. S decompensated due to fungemia. The IDT agreed that death was imminent, even with dialysis. With application of the FHCDA it was ethically appropriate to withhold dialysis and transition Mr. S to comfort care.

**Conclusion:** Utilizing the four-box approach to decision-making and an interdisciplinary team, providers can manage un-befriended patients with an organized, ethically sensitive, and legally sound framework.

## ***“No Hablo Inglés” Does Not Mean, “Do Not Treat”*: Providing Palliative Care to an Undocumented Immigrant (SA518B)**

Megan Rau, MD MPH, Mount Sinai Hospital, New York, NY

Emily Chai, MD, Icahn School of Medicine at Mount Sinai, New York, NY

Nicole Elitch, BSN ACHPN ANP GNP, Icahn School of Medicine at Mount Sinai, New York, NY

### **Objectives**

- Identify the critical role an interdisciplinary team plays when caring for an undocumented immigrant including nontraditional members such as interpreters, legal departments and ethics committees.
- Highlight the limited availability of hospice resources for an undocumented immigrant who is imminently dying and the difficulties associated with providing high value palliative care.

**Background:** Access to medical care for the 11 million undocumented immigrants residing in the US is severely limited and can be characterized by language barriers, poverty, inadequate social support networks, and lack of insurance coverage. Charity care options for undocumented patients may be available, and in some states Emergency Medicaid will cover hospitalizations. However, limited access to palliative care and hospice causes distress and suffering for terminally ill undocumented immigrants and adds a significant financial burden to safety-net providers.

**Case Description:** A 42 year-old Mexican man with alcoholic liver failure and encephalopathy was admitted for liver transplant. He was subsequently intubated and developed renal failure requiring dialysis. He was not a liver transplant candidate due to lack of insurance and absence of socioeconomic support necessitating a Palliative Care consultation. Social work confirmed he was a homeless undocumented immigrant with no known contacts who had been in the US for eight years. An interpreter helped determine he lacked capacity and had no healthcare proxy. The Embassy was unable to locate next-of-kin. A legal consultation was initiated due to complex decision-making in the context of his grim prognosis. Given his irreversible disease and no available therapy, authorization for DNR was completed. Despite the interdisciplinary team’s exhaustive efforts to enroll him in hospice, he decompensated before an inpatient bed accepted him. At the time of death, six weeks after his first contact with the US health system, he died with no next-of-kin to notify, no surrogate decision maker, and no insurance.

**Conclusion:** A mechanism must be developed in the US healthcare system to provide hospice and palliative care to undocumented immigrants. The complexities of treating this population require the expertise of an

interdisciplinary Palliative Care team, which will align patient care needs with appropriate treatments that increase quality of life, decrease unnecessary resource utilization, and prove cost effective.

## ***Collective Approach to Cultural Competency: A Case of Challenge in Decision-making in Amyotrophic Lateral Sclerosis (SA518C)***

Evgenia Krotova, MD, Beth Israel Medical Center, New York, NY

Rana Zahiri, MD, Columbia University Medical Center, New York, NY

Craig Blinderman, MD MA, New York Presbyterian Hospital, New York, NY

### **Objectives**

- Describe conflict in patient autonomy-centered western medicine with cultures with family-centered decision-making.
- Describe culturally-sensitive approaches to discussing long-term life support in advanced amyotrophic lateral sclerosis.

**Background:** Decision-making in advanced amyotrophic lateral sclerosis (ALS) is complex, and may highlight the conflict between patient autonomy and cultural interface in context of advancing technology. Prolonged ventilator support and feeding via percutaneous gastrostomy has the potential to prolong survival in ALS patients. Little data exists to enhance understanding of the socio-cultural factors influencing a patient's decision to pursue such measures within the western medicine construct of patient autonomy.

**Case Description:** A 45-year-old Polish female with advanced ALS, bedbound, non-verbal, was admitted with respiratory failure due to aspiration. She retained motor function in her eyes only, and used eye tracking device to communicate. Prior discussions with outpatient ALS team outlined patient declining non-invasive ventilation and artificial nutrition. Upon admission, she expressed wish to be DNR/DNI, however when her condition deteriorated, she was intubated at her spouse's insistence. Spouse denied knowledge of her previously stated wishes. She was not able to be weaned off ventilator support due to profound respiratory muscle weakness; therefore options for palliative extubation or continuing ventilator support via tracheostomy were considered. Multiple family conferences were held to ascertain patient's wishes, with participation of palliative care, primary medical, outpatient ALS teams, ethics, speech pathology, and professional interpreters. Decision-making process was complicated family stating that in their culture decisions are made in family unit, without emphasis on patient's own wishes. Patient initially stated her quality of life is dismal, and requested palliative extubation. After discussions with spouse and father, she expressed ambivalence. Ultimately, she asked to allow tracheostomy and percutaneous gastrostomy placement, stating she wished to continue life-sustaining measures to remain alive for her spouse and children.

**Conclusion:** Advance care planning in ALS is a challenging process that requires frequent goals reassessment. Culturally sensitive approaches are necessary to balance respect for patient's autonomy with family unit centered decision-making.



## ***Autonomy Threatened: Personality Disorders in Medical Crisis (SA528A)***

Ayla Pelleg, MD BS, Chicago, IL

Josh Baru, MD FACP, John H. Stroger Hospital, Chicago, IL

### **Objectives**

- Define the criteria for decision-making capacity.
- Understand the effects of medical crises on decision-making for patients with personality disorders.

**Background:** Respect for autonomy, a foundational principle in medical ethics, demands a reciprocal duty to protect vulnerable populations. Decision-making capacity is a prerequisite for autonomous action; patients lacking decision-making capacity are vulnerable. Patients with Antisocial and Borderline personality disorders (PD) are defined by impulsivity and harm to self or others. When faced with medical crises, these maladaptive behaviors are exaggerated and patients' coping and problem solving skills are impaired. In medical crises, patients with PD may not be able to delineate their own true desires and, thereby, lack decision-making capacity.

**Case Description:** A 23 year-old man with a cluster B personality disorder not otherwise specified (NOS) had an implantable cardioverter defibrillator (ICD) placed for sudden cardiac death due to Arrhythmogenic Right Ventricular Dysplasia (ARVD). Shortly after implantation, the patient was incarcerated. While incarcerated, the patient stabbed his device pocket with a pen. His ICD became infected. Attempts to sterilize it with intravenous (IV) antibiotics failed. An infectious disease consultant recommended removal of the ICD to prevent death from overwhelming sepsis. The patient agreed to removal on three occasions; withdrawing consent on the day of treatment each time. His reasons for refusal varied. He also intermittently refused nursing care, blood draws, and IV antibiotics. He was able to relate the proposed reasons for removal and the expected outcomes of his refusals. As his death was expected, the Palliative Care team was consulted to assist with goals of care.

**Conclusion:** In medical crises, patients with PD have impaired coping and problem solving skills. This can affect their ability to reason rationally and, consequently, undermine decision-making capacity. Providers must rely on alternate decision-makers for patients lacking decision-making capacity. Palliative care consultants may care for patients with PD with self-inflicted life-threatening diseases. Recognizing the limits of decision-making capacity is necessary when addressing goals of care.

## ***Uncharted Territory: The Wrenching Need to Separate a Suicidal Child from Her Actively Dying Mother (SA528B)***

Bridget Tracy, MD, Palliative Medicine, New York, NY  
Jacqueline Peare, MSW, Mount Sinai Hospital, New York, NY  
Sarah Yazdian, LCAT, CCLS, Mount Sinai Hospital, New York, NY

### **Objectives**

- Identify the need for diverse interdisciplinary teams in the care of adult palliative care patients and their families.
- Describe how interdisciplinary teams contribute to resilience and provider safety in the face of conflicts.

**Background:** In palliative medicine, the unit of care includes both the patient and the family. In most cases, the patient is at the center of the team's efforts to provide the best possible interdisciplinary care. We report here on a case where the emergency needs of an actively suicidal child became the urgent focus of care.

**Case Description:** Ms. AL, a 54 year old patient on our Palliative Care Unit, was actively dying. KL, her 12 year old daughter, was referred to our Art Therapist/Child Life Specialist (CLS) for anticipatory grief. KL disclosed apprehension about moving in with her estranged father, sadness over her mother's illness, and thoughts of harming herself. The CLS and team social worker assessed for suicidal ideation and found KL had a pattern of self-injury, easy access to her mother's pain medications, and a plan to end her life. The interdisciplinary team members agreed that KL's safety was a priority, but an emergency intervention would cause a wrenching separation from her mother during the final moments of AL's life. After discussions with supervisors in child life and social work, and a child psychiatrist, the team agreed that KL needed immediate evaluation and treatment. KL's father and godmother were initially angry and verbally abusive when advised of KL's need for emergency treatment. After further discussion about the importance of urgent action, her family agreed to immediate evaluation by the pediatric emergency team.

**Conclusion:** Caring for our actively dying patient was proceeding along a familiar path, until a child in peril took our team in an unfamiliar direction. Adult palliative care teams must be also prepared to identify and address the emergent clinical needs of family members of patients, including children, who may be at risk for acute emotional distress as their loved one approaches the end of life.

## ***Treatment of a Suicide in Progress with Ketamine to Allow Family Therapy before Death (SA528C)***

Kate Westmoreland, MD, Legacy Health, Portland, OR  
Michael Zalanka, MD, Legacy Health System, Portland, OR

### **Objectives**

- Recognize ethical issues around goals of care and proxy decision-making in the palliative care of a patient whose clinical situation is a "suicide in progress".
- Understand the use of ketamine in acute depression and in acute pain.
- Build acceptable and achievable goals of care for a patient whose suicide will complete.
- Recognize issues of provider countertransference and staff moral distress in the care of a patient who has chosen suicide over life with disability and an unacceptable body image.

**Background:** Palliative care providers routinely participate in the care of many ICU patients, but it is relatively uncommon to be involved in the medical care of patients after attempted suicide. Psychiatrists routinely care for patients following suicide attempts, but are rarely forced to exchange effective depression treatment for anticipatory bereavement therapy. This case examines the ethical, pharmacological, and countertransference challenges of such a case.

**Case Description:** Mr. L, a happy and productive executive athlete suffers a thoracic spinal cord injury while on a business trip to Thailand; roadside, he is paralyzed. Following several surgeries and many months of rehabilitation, he achieves a remarkable functional recovery. He can walk half a mile, with crutches, and complete his ADLs independently.

But what would be an acceptable outcome for others proves enormously distressing for him. He perceives himself as incapacitated and deformed, "a useless freak". After two years of aggressive medical care, Mr. L presents to a suburban ICU following his second suicide attempt. He suffers the sequelae of bleach ingestion and subsequent esophago-pleural-cutaneous fistula. Symptoms include acute pain, chronic neuropathic pain, and mixed delirium. Mr. L's wife is his proxy decision-maker, and their several years of shared misery complicate the process of substituted judgement.

Collaborative palliative care and psychiatric consultation is obtained. I.V. ketamine is infused twice daily to address acute pain, depression and delirium. It is successful. Mr. L is able to converse fluently and with some insight about his situation. He remains actively suicidal. Mr. and Mrs. L refuse to consent for surgery to attempt

repair of his esophagus. The family receives psychiatric therapy at the inpatient hospice unit, where he dies peacefully. Provider distress leads to exploration of countertransference issues.

**Conclusion:** Patients completing a suicide which cannot be interrupted can still benefit from palliative and psychiatric consultation.